# PSYCHONEPHROLOGY: A DESCRIPTIVE ANALYSIS OF THE BIOPSYCHOSOCIAL FACTORS THAT INFLUENCE PATIENT ADJUSTMENT TO CHRONIC HEMODIALYSIS

A THESIS

SUBMITTED TO THE FACULTY OF ATLANTA UNIVERSITY

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR

THE DEGREE OF MASTER OF SOCIAL WORK

BY

DORIS J. JOHNSON

SCHOOL OF SOCIAL WORK

ATLANTA, GEORGIA

JUNE 1989

R-V p=58

ABSTRACT

SOCIAL WORK

JOHNSON, DORIS J. MSW ATLANTA UNIVERSITY 1989

PSYCHONEPHROLOGY: A DESCRIPTIVE ANALYSIS OF THE BIOPSYCHOSOCIAL FACTORS THAT INFLUENCE PATIENT ADJUSTMENT TO CHRONIC HEMODIALYSIS

Advisor: Professor Mary C. Ashong

Thesis dated: June, 1989

The overall objective of this study is to describe the adjustment patterns of hemodialysis patients and the role of support systems in influencing the outcome of End Stage Renal Disease. To attain this objective, the following areas on hemodialysis were addressed by the researcher: (1) psychological control, (2) positive interpersonal behavior, (3) independence, (4) understanding of medical regimen, (5) acceptance of treatment restrictions, (6) compliance to medical regimen, (7) compliance with dietary regimen, and (8) active involvement in treatment. A discussion on social support satisfaction in the areas of family/significant other relations, financial resources, and community service networks will also be presented. Two descriptive research designs were used in the study.

Each of five nurses independently evaluated 25 patients using the Patient Adjustment to Dialysis Checklist (PADC) at an outpatient dialysis facility in the Macon area. The social worker evaluated the same 25 patients using the Social Support Satisfaction Checklist (SSSC). A population of males and females were provided dialysis services by the facility three times a week.

This study was an attempt to describe some of the characteristics of hemodialysis patients' adaption to treatment and to discuss interventions which might help to enhance a more stable psychosocial adjustment.

ACKNOWLEDGEMENTS

To all people with Kidney disease.

I am grateful to all the medical and health-care professionals for their on-going support over the year and for sharing their knowledge, experience, and insight into the problems confronting people with kidney failure.

A special thanks to my advisor, Professor Mary Curtis Ashong, and other Atlanta University School of Social Work faculty for their highly esteemed knowledge and encouraging support throughout graduate school where this project was conceived.

TABLE OF CONTENTS

LIST OF TABLES

# CHAPTER ONE

## INTRODUCTION

In the United States today, more than 90,000 people are diagnosed with Chronic Renal Failure. This condition has the same meaning as the term End Stage Renal Disease. When kidney failure is lost, either some form of dialysis or kidney transplant is needed to maintain life.

Abram (1981) states that chronic illness negatively impacts on almost every aspect of a patient's life. This is particularly true among chronic hemodialysis patients who typically must change their entire lifestyle due to the nature and effects of treatment. Necessary lifestyle changes are often in conflict with desires of most patients to be independent and productive. Patients with kidney failure have a catastrophic and fatal illness, their only hope for survival is through dialysis. They must adjust to the multiple restrictions of dialysis and must learn to live with chronic illness and the possibility of imminent death. (Heard,1969).

## STATEMENT OF THE PROBLEM

The National Kidney Foundation estimates that over seven million Americans now suffer from disease of the kidney (National Kidney Foundation, Inc. 1987). The long periods of chronic illness, repeated hospitalizations, and the overwhelming amount of stress placed on patients and families have implications for social work practice.

The physical condition and health of a client constitute one of the important areas of the total situation that the social worker must consider in diagnosing and planning treatment. The task is to assess the extent to which the life patterns, problems, and potential for psychosocial functioning are presented by the client and affected by his physical condition.

Psychosocial adjustment problems have been reported to be common among hemodialysis patients. They experience fear of death, feelings of dependency, stress, helplessness, anger and hostility (Nadelson, 1971). Family members face many of the same emotional stresses and problems as patients including; depression, anxiety, concerns for the patient's life expectancy, concern about finances, difficulty in

expressing honest feelings, and sexuality concerns. (Whalen, 1978). A significant factor in the presentation of this study is to consider how the availability of support systems affect the biopsychosocial adjustment of hemodialysis patients.

The social worker has an essential contribution to make to the total treatment plan. The new developments present a challenge to social workers to use their skill and knowledge to assist patients to obtain the greatest benefits from medical care and to participate in the wholesome living that new treatments provide.

## Significance/Purpose of the Study

The aim of the present study is to describe the factors that influence adjustment to dialysis and the effect of compliance, cooperation, and family support on patient adaptation. Although patients are thought to experience a life-death conflict in response to the news of having End Stage Renal Disease, individuals differ. Living as a disabled person, totally dependent upon a machine for continuation of life, is an enormously difficult adjustment to make and the prospect of doing so can be just as frightening and overwhelming as the prospect of dying. The incorporation of patient values, self-determination, and dignity must be an integral part of the decision to accept dialysis. Social work intervention can play a significant role in facilitating effective adaptive behavior.

The dynamics of the changing health structure make it imperative that social workers examine our role and function. In addition to providing psychosocial evaluations and therapeutic interventions, medical professionals will be expected to be more active and verbal in the therapeutic context and make expanded use of family and other support systems. The moral,

ethical, and practice issues involved in helping patients and families to resolve difficulties caused by End Stage Renal Disease have a profound effect on techniques and functions of social work. It is incumbent on us to define our role and responsibilities in a thoughtful, comprehensive, and professional manner and to assume our share of responsibility to make contributions in our dialysis settings.

# CHAPTER TWO

## REVIEW OF THE LITERATURE

The treatment of End Stage Renal Disease (ESRD) was revolutionized by the development of the artificial kidney in the late 1950's and by the feasibility of transplantation after the introduction of immunosuppressive agents (Ford, 1977). Hemodialysis has become a routine procedure in major hospitals and kidney transplants are performed regularly at most medical centers (Stewart, 1983). The majority of ESRD patients receive hemodialysis in a clinic or hospital. Only 13% of the dialysis patients in this country dialyze in their own home (Katz, 1969).

Treatment with dialysis is necessary when a person experiences kidney failure or when both kidneys are working below normal 5th percentile. There are two basic kinds of dialysis - hemodialysis and peritoneal dialysis.

Hemodialysis or artificial kidney treatment is a procedure which removes fluids and waste products directly from the bloodstream. An access device is

implanted in the arm or leg, and blood is taken from an artery through a needle which has been inserted into the access device. A tube is attached to the access device and is carried to the dialysis machine. The heart pumps blood with the assistance of a blood pump through the tube to the machine, where it is cleansed by running through a dialyzer (artificial kidney) and returned to the body through a tube and through a needle which has been inserted into a vein. The blood is continuously circulated, a pint at a time through the dialyzer until the treatment has been completed. The time required for each hemodialysis treatment is determined by the patients amount of remaining kidney function, fluid weight gain between treatment and the build up of harmful chemicals between treatments. On the average, each hemodialysis treatment lasts approximately 3-4 hours and is necessary three times per week.

How long can a person live on dialysis? There are many patients who have been on chronic dialysis since it was widely available in the 1960's. (National Kidney Foundation, 1987). The total life expectancy remains unknown, but some dialysis patients may approach normal life spans. However, some patients do not tolerate

dialysis well and have many complications (National Kidney Foundation, 1987).

Another major treatment for kidney failure is kidney transplantation. This involves removing a kidney from either a living relative or from an unrelated deceased person and surgically placing the new kidney into the patient. Transplantation promises a rebirth to patients on dialysis (Rodin, 1987).

One of the most crucial questions that dialysis patients are faced with is, "How will having kidney failure change my life?" (Farris, 1981). This question is difficult to answer because each person will react differently to his or her kidney failure and treatment. Farris further states that to live with dialysis may be a minor adjustment for some or may demand a major change in lifestyle and philosophy. An important change in a person's life will require altering habits, priorities, schedules, and outlook. Some people with chronic illness will experience some degree of depression and anxiety about their uncertain future. These experiences are associated with changes in sexual functioning, body image, work, and recreational activities which often come with hemodialysis. As patients become more familiar and comfortable with

their treatment, they are able to deal with their feelings and concerns, kidney failure and treatment become a part of their lifestyle.

Both patient and family worry about what will happen in the household if the patient dies or is incapacitated. This is a major concern if the patient is a bread winner.

## Psychological Control

Most people with chronic illness will experience some degree of depression and anxiety about their uncertain future. Everyone with renal failure experiences several stresses. The stresses most commonly discussed are: impairment of physical functioning, changes in financial status and way of life, loss of social group membership and other roles, threat of injury, difficulty in planning the future, and the basic drives of sex, hunger, and thirst are frustrated (Nomberg, 1987). Since kidney failure and treatment is a chronic condition, not a terminal one, people may also experience feelings of sorrow grief, confusion, fear, and even anger (Farris, 1981).

This is usually a time of severe emotional upheaval and adjustment, touching all parts of their

lives. In addition to feeling weak and depressed, the patient and family may be confronting changes in self perception, family relationships, and vocational roles. Facilitation of patient adjustment is clearly indicated as an important part of patient care and has significant focus for the social work practitioner.

There is no specific way of coping with kidney failure and treatment. Each individual has a different experience, varying attitudes toward dialysis and coping with a chronic illness. Some examples of ways that people have found to ease adjustment to chronic illness and treatment include: education about kidney failure and treatment, physical fitness, communication in maintaining personal relationships and motivation to complete projects and goals.

Denoor (1976) is one investigator who views depression as the most common psychological complication of dialysis. Depression, or feelings of sadness, unhappiness, and despair can occur with negative change, loss, and illness. Depression can cause a loss of appetite, decreased interest in sex, and difficulty in talking about the problem. The emotional state of a person can affect their physical

health, and in the case of kidney failure, medical treatment and progress. If the emotional state or mental attitude is positive, patients will tend to do well on dialysis. If however, they have a difficult time adjusting, or had problems prior to dialysis, they will not do as well on dialysis as someone with a positive mental outlook.

Patients use several defense mechanisms to ward off overwhelming anxiety, including denial, displacement, isolation, projection, and reaction formation. Denial is the most frequently used defense against the stress of chronic illness (Glassman, 1970). Examples of emotional control in patients include mature interpersonal behavior with family, no excessive thoughts about illness, and discussion of illness with staff.

## Positive Interpersonal Behavior

The crisis of illness may cause significant family and marital problems due to the sudden demands of hemodialysis or the illness may also help a couple become closer as it provides them a common enemy to fight together (Abram, 1972). In either case, there are changes in the couples relationship as each copes with

anger, fear, resentment, weakness, strengths, love, and possible changes in sexual relationship. According to (Bommer, Tschope, Ritz, et. al., 1976) chronic illness often affects the marital dyad.

While the patient's dependency needs are gratified, the role change results in feelings of demoralization, lowered self-esteem, and depression. For males, impotence is the major sexual problem, followed by loss of libido (Rodin, 1987). In the study by Abram and others about 45 percent of patients developed impotence secondary to uremia before dialysis. While dialysis improves the general sense of well-being, an additional 35 percent will develop impotence. The marital situation prior to this time greatly affects the couple's response.

Isolation may become a problem, as a spouse may not be available to share some of the immediate feelings, or to meet with the helping professionals due to distance, work, or childcare responsibilities. He or she then feel estranged or even guilty about his limited involvement and knowledge. The patient may resent having to carry the burden alone or may try to protect the family by withholding information creating tension of another kind. Examples of positive

interpersonal behavior in patients are: does not display inappropriate anger towards family and/or staff, cooperates with staff, and exhibits a friendly, pleasant personality.

## Independence

At the same time as patients and families are dealing with the new medical situation, they are fearfully anticipating physical restrictions that will affect their jobs, retirement plans, social life, travel, eating patterns, and the cost of treatment. Dialysis is very expensive. Fortunately, through the efforts of the National Kidney Foundation the federal government now pays 80% of all dialysis costs and private health insurance or state medical assistance is often available to anyone who needs it. Work is usually the main concern. If unemployed, patients may be afraid to reapply for jobs for fear of failing. They may not be collecting all the benefits due to them, or they may be unaware of the rehabilitation programs available. Even if they are not worried about job performance, there may be concerns about promotion,

work scheduling, or special job demands like travel. (Lubell, 1978).

In a survey of 2,481 patients, (Gutman, Stead, Robinson, (1981) found that only 34 percent of patients were working while on dialysis, and 20 percent were unable even to take care of their own personal needs. Educational achievement and previous job record are the major determining factors in vocational rehabilitation. Also in the Gutman survey 55 percent of males with skilled jobs were employed, compared with 27 percent of workers with unskilled jobs. As a rule, patients who do not return to work after six months of dialysis will never do so (Malmquist, 1972). Examples of independence in patients may be mature interpersonal behavior with staff, interaction with other patients at the center, and questioning the medical charts and regimen.

## Understanding of Medical Regimen

End Stage Renal Disease (ESRD) is a serious medical condition that is fatal unless treated with dialysis or transplantation. In the absence of a functioning kidney transplant, survivial with this condition requires maintenance dialysis, dietary regulation, medications, and other measures to maintain

physiologic hemeostatis (Reichsman, 1972). Often when a patient initiates dialysis, he is feelings physically debilitated and emotionally drained. This condition makes it difficult to deal with the medical system, as he may feel overwhelmed by the technology and procedures. Examples of understanding of medical regimen include understanding the need for dietary restrictions and fluid restrictions.

## Acceptance of Treatment Restrictions

Non-compliance may arise as a result of several factors, including the stress in maintaining a rigid diet. Fresh fruits must be avoided because of high potassium content, and fluid and salt intake are restricted to prevent fluid overload and congestive heart failure. Secondary heperparathyroidism limits the consumption of milk products. Dietary control however, is of paramount importance for good medical management. Fluid overload creates sudden shifts in electrolyte balance during dialysis, resulting in nausea, dizziness, headache, and muscle cramps (Procci, 1981). Even so, restrictions on fluid intake are most frequently ignored. Examples of acceptance of

treatment restrictions are: not overly anxious about treatment and arrival on time for treatments.

## Compliance to Medical Regimen

Dialysis improves and relieves many, but not all, of the symptoms of kidney failure. The degree of relief varies from patient to patient. Many patients lead near normal lives except for the need to have treatments (Kuther, 1981). Emotional adjustment of the patient and family does take time and understanding. Counseling and assistance with coping skills is very important. The role of the social worker is to help facilitate the patients expression of feelings and concern, and to involve the family in the comprehensive treatment plan. Examples of compliance to medical regimen consists of complying with physician's orders, taking medications as prescribed, and being present for all treatments.

## Compliance with Dietary Regimen

Fluid noncompliance is a remarkably stable phenomenon, and patients whose noncompliance is intermittant are in the minority. As related to social work practice, while intermittant and occasional to

psychotherapeutic intervention, the problem of chronic or stable fluid overloading is exceptionally resistant to such intervention (Agashua, Lyle, 1981). Examples of compliance with dietary regimen are compliance with fluid intake restrictions and dietary restrictions.

## Active Involvement in Treatment

The ability for patients to have some responsibility for the course of their treatment is important in one's psychosocial adjustment. Examples of active involvement in treatment include participation in selfcare techniques such as holding needle sticks, and expressing interest in home dialysis or transplant.

## Overview of the Major Theoretical Orientation

The major functions of the social worker are to help the hemodialysis patient face his current environment and work through his feelings, fears, and attitudes and to help him strive toward a realistic adjustment and plan for his future life. The social worker uses skills to explore the interactions and dynamics of members of a family; their attitudes, ways of communicating, and patterns of coping. The focus is

on helping families retain their integrity and functions.

The dialysis patient may feel uncomfortable either asking for support from the spouse or depending on him/her. The patient may then compensate by being quite demanding or by shutting out the spouse, not letting him/her get too close. In response, the spouse may feel awkward, isolated, or helpless, either misunderstanding or worrying about what she should be doing to help.

Using the family systems model, when a tramatic, stressful event occurs within a home, homeostatis within the family system has been disturbed. There is a loss of balance to maintain and preserve the system.

Family problems and crisis create considerable stress and require adaptive responses in order to cope. Dialysis patients and their families often feel immobilized and may tend to respond inadequately or inappropriately for the demands of the situation. According to Janzen (1986) a family's capacity for a sense of cohesion or unity, and adaptability or ability to meet obstacles and shift course is essential for problem solving (Janzen, Harris, 1986). The dimensions of cohesion may indicate separated and connected

relationships related to emotional bonding, coalitions, and decision-making. A more healthy dimension of adaptability could range in acceptable degrees from flexible to structured and may be manifested by assertiveness, leadership, and negotiation. Janzen further states that problem solving is contingent upon the family's communication capacity, changing role requirements, family values, and effectiveness and quality of family leadership.

The goal of the social worker in providing services to a family unit experiencing a life changing condition is to understand the nature of the presenting problem and engage family members in the treatment effort. Interventions with the dialysis patients help them and their families focus on resolving difficulties caused by End Stage Renal Disease.

Family systems theory may be utilized to assess how all the family members operate together during the time of crisis and to enhance problem-solving capacities. The patient is a sub-system of a larger sub-system, the entire family unit. Efforts to have family members understand, discuss, and share their feelings related to illness are paramount in the

patient and the family's overall adjustment to a life-changing illness.

## Definition of Terms

Stable adjustment to dialysis will be defined as psychological well being and relative freedom from dialysis-related stresses. The patient's restoration of optinal qualify of life includes acceptable compliance to the dialysis regimen i.e., three times a week treatment, consistent medication therapy, and compliance to diet and fluid restrictions.

The measure of social support is based on Cobb's (1976) notion of social support as "information" that one is loved and cared for, esteemed and valued, and part of a network of communication and mutual obligations.

The Social Support Satisfaction (SSS) Checklist was developed to assess the size of subjects' social network, the importance to the individual of the types of social support, and the level of satisfaction with each type.

## Statement of the Hypothesis

The relationship between human beings and their social milieu is dynamic and exceedingly complex and can contribute to differing health outcomes (Wai, Richmond, 1976). The significance of social systems

has been most clearly demonstrated in the areas of biopsychosocial dimensions. These studies suggest an association between a supportive interpersonal environment, recuperation, and the capacity to endure serious physical illness. Others have shown that individuals with relevant social ties are healthier than those lacking them (Sand, Livingstone, 1966). Primary group support cushions an individual against biological and psychosocial stressors. (Pentecost, Zwevens, Manuel, 1976). These findings suggest that support systems can affect the experience, course, and outcome of a renal regimen.

There is documented evidence of a positive association between supportive family attitudes and successful adaption (Burton, 1983) and between family stability and intrafamily identity with all aspects of adjustment (Diamond, 1979). There is concensus in the literature that the absence of a supportive environment is problematic for the dialysis patient (Turner, 1983).

## Statement of the Hypotheses

There is no significant relationship between social support systems and social adjustment in hemodialysis patients.

There is no significant relationship between social support systems and psychological adjustment in hemodialysis patients.

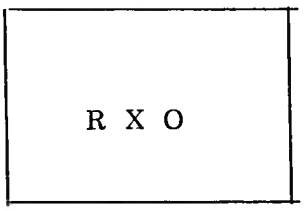
There is no significant relationship between social support systems and medical adjustment in hemodialysis patients.

# CHAPTER THREE

# METHODOLOGY

## Research Design

The diagramatic presentation of a cross-sectional study describing the plan, structure, and strategy to obtain various research questions may be seen below:




R = Random sample of the population

X = Administration of independent variable

O = Observation of dependent variable

The design will be utilized in the study to show that there is no significant relationship between the availability of social support systems and social adjustment in hemodialysis patients, psychological adjustment in hemodialysis patients, and medical adjustment in hemodialysis patients.

## Research Setting

The population from which the sample was drawn included twenty five patients who receive chronic hemodialysis treatments at Macon Dialysis Facility, five Registered Nurses, and a Masters Level Social Worker.

Macon Dialysis Facility, Inc. is a chronic-out patient dialysis facility which provides artificial kidney treatment and support services for 72 persons with Chronic Renal Failure, located in Macon, Georgia. It had approximately 6 nurses and 8 technicians on staff; and there was an average daily census of 62 patients who dialyzed 3-4 hours, three days a week on the Monday-Wednesday-Friday shift; and between 8 - 10 patients who dialyzed on the Tuesday-Thursday-Saturday morning shift.

## Sampling

The selection procedure for patients participating in the study was determined by probability sampling. The sample contained the same distribution of variables of substantive concern to the study as did the population. Alternate choices were made on each patient in the dialysis unit from the Monday -

Wednesday-Friday morning and afternoon shifts, and from the Tuesday-Thursday-Saturday morning shift. The criterion for patient participation was based on more than three months homodialysis experience.

## Data Collection Procedure

The Patient Adjustment to Dialysis Checklist (PADC) was administered to each of the five nurses evaluating the 25 patients. It contained 44 statements utilizing the Likert-type scale. The Social Support Satisfaction Checklist (SSSC) was designed by the researcher to be completed by the social worker. It contained 18 statements and was a composite of several measures with internal consistency. The responses ranged from strongly agree to strongly disagree.

Each rater using the PADC was requested to indicate the level of agreement for those attitudes and behaviors characteristic of a patient in the areas of psychological control, positive interpersonal behavior, independence, understanding of medical regimen, acceptance of treatment restrictions, compliance to medical regimen, compliance with dietary restrictions, and active involvement in treatment.

On the SSSC used by the social worker, information was obtained on the patient's demographic profile (i.e., age, sex, race, years of experience on dialysis, etc.). The rater was requested to indicate the level of agreement for those attitudes and behaviors characteristic of a patient in the areas of family/significant other relations, financial support systems, and community support network.

In terms of reliability, a factor analysis was performed on checklist data from 106 nurses' responses in a nationally distributed article when asked to rate the importance of attitudes and behaviors for adjustment of hemodialysis. Eight groups of significantly correlated items resulted. Thus, eight factors appear to be important in patient adjustment, resulting in the Patient Adjustment to Dialysis Checklist.

The Social Support Satisfaction instrument is new and was not pre-tested; but was constructed consistent with the literature reviewed. It is believed that the instrument measured what it was intended to measure (i.e., dialysis patients' satisfaction with social support systems as it related to their social, psychological, and medical adjustment).

## Data Analysis

A chi-square test was used to determine if there is a relationship between social support systems and the independent variables. The hypotheses tested in this research were; (1) there is no significant relationship between social support systems and social adjustment, (2) there is no significant relationship between social support systems and psychological adjustment, and (3) there is no significant relationship between social support systems and medical adjustment in chronic hemodialysis patients.

The chi-square valve calculated for social adjustment equalled 6.4. The critical chi-square at the .05 probability level was .01, for one degree of freedom. Therefore, the null hypothesis was rejected and the investigator's hypothesis was supported. The chi-square valve calculated for psychological adjustment equalled 7.8. The critical chi-square at the .05 probability level was .005, for one degree of freedom. Therefore, the null hypothesis was rejected and the investigator's hypothesis was supported. The chi-square valve calculated for medical adjustment equalled .53. The critical chi-square at the .05 probability level was .46, for one degree of freedom.

Therefore, the null hypothesis was supported and the investigator's hypothesis was rejected.

TABLE I

PATIENT ADJUSTMENT TO DIALYSIS CHECKLIST

Assessment of Adjustment

Instructions: Indicate the level of agreement for those attitudes and behaviors characteristic of patient.

A=Agree SA=Strongly Agree N=Not Applicable
D=Disagree SD=Strongly Disagree

| | | |
|---|---|---|
| 1. | PSYCHOLOGICAL CONTROL | |
| | establishes a meaningful daily routine | ( ) |
| | involved in outside activities | ( ) |
| | continues with age appropriate activities | ( ) |
| | perceives self as a total person | ( ) |
| | mature interpersonal behavior with family | ( ) |
| | discusses illness with family | ( ) |
| | healthy independence from family | ( ) |
| | maintains social life | ( ) |
| | no excessive thoughts about illness | ( ) |
| | accepts reality of disease/dialysis | ( ) |
| | exercises regularly | ( ) |
| | discusses illness with staff | ( ) |
| 2. | POSITIVE INTERPERSONAL BEHAVIOR | |
| | shows no inappropriate anger towards staff | ( ) |
| | no excessive phone calls to unit about health | ( ) |
| | cooperates with staff | ( ) |
| | does not exaggerate complaints | ( ) |
| | does not manipulate complaints | ( ) |
| | is seldom depressed | ( ) |
| | exhibits friendly, pleasant personality | ( ) |
| 3. | INDEPENDENCE | |
| | mature interpersonal behavior with staff | ( ) |
| | shows healthy independence from staff | ( ) |
| | interacts with other patients at center | ( ) |
| | questions medical charts and regimen | ( ) |

TABLE I (cont'd)

| | |
|---|---|
| 4. UNDERSTANDING OF MEDICAL REGIMEN | |
| understands need for restricted fluids | ( ) |
| understands need for dietary restrictions | ( ) |
| 5. ACCEPTANCE OF TREATMENT RESTRICTIONS | |
| not overly anxious about treatment | ( ) |
| no psychological difficulties regarding machine | ( ) |
| arrives on time for treatments | ( ) |
| 6. COMPLIANCE TO MEDICAL REGIMEN | |
| complies with physicians orders | ( ) |
| takes medication as prescribed | ( ) |
| present for all treatments | ( ) |
| does not abuse alcohol or drugs | ( ) |
| demonstrates good hygiene practices | ( ) |
| interest in gaining knowledge of illness | ( ) |
| 7. COMPLIANCE WITH DIETARY RESTRICTIONS | |
| shows healthy independence from staff | ( ) |
| complies with fluid intake restrictions | ( ) |
| complies with dietary restrictions | ( ) |
| 8. ACTIVE INVOLVEMENT IN TREATMENT | |
| expresses interest in home dialysis | ( ) |
| does self-care during treatment | ( ) |
| holds own needle sticks | ( ) |
| serious thoughts about kidney transplant | ( ) |
| participates in treatment | ( ) |
| not overly anxious about needle sticks | ( ) |
| seeks outside contact with dialysis patients | ( ) |

TABLE 2

SOCIAL SUPPORT SATISFACTION CHECKLIST

Demographic and Social Data

---

Name_____ Age_____

Race and Sex

Black Male ( )
Black Female ( )
White Male ( )
White Female ( )

Marital Status

Single ( )
Married ( )
Separated ( )
Divorced ( )
Widowed ( )

Living Situation

Living With Partner ( )
Living Alone ( )

Work History

Currently Employed ( )
Reason for discontinuing work ( )

Ill Health ( )
Normal Retirement ( )
Early Retirement ( )
Poor Pay ( )

---

Assessment of Adjustment

Instructions: Indicate the level of agreement for those attitudes and behaviors characteristic of patient.

1. FAMILY/SIGNIFICANT OTHER RELATIONS

exhibits a friendly, pleasant personality with family/significant others ( )
shows positive interpersonal behavior with family/significant others ( )
establishes a meaningful daily routine ( )
relies or depends on family/significant other ( )
looks for help from friends ( )
feels appreciated by others ( )
feels that he/she is needed ( )

feels that family/significant others are very important in his/her life ( )
feels that family/significant others really care ( )
talks about illness with family/significant others ( )
copes effectively with stresses of illness ( )
exhibits phychological wellbeing ( )

2. FINANCIAL SUPPORT SYSTEMS

uses financial resources provided by organizations to help with kidney related needs ( )
uses personal resources for kidney related needs ( )

3. COMMUNITY SUPPORT NETWORK

uses transportation services to dialysis ( )
uses DFACS services for kidney related needs ( )
uses OAC services for recreational and socialization needs ( )
uses NSC services for supplementary needs ( )

# CHAPTER FOUR

## PRESENTATION OF RESULTS

The results of this study are shown in the Appendices (Tables 3 through 5). The results derived from this research indicate that the utilization of social support systems may enhance successful adjustment in the areas of social and psychological functioning in chronic hemodialysis patients. They further suggest that adequate availability of resources aids in compliant behaviors, and that praise and positive interaction may be helpful in educating and encouraging the patient to follow the medical regimen.

The composition of the sample included 19 Blacks and 6 Whites, with 11 males and 14 females. 9 were married, 3 were separated, 2 were divorced, and 4 were widowed. 7 of the patients were single and only one was employed. The respondents ranged in age from 24 to 73 with an average age of fifty-four years. The duration on hemodialysis varied from a minimum of six months to a maximum of eleven years and five months. (See Table 1)

The eight major areas of the 44 item Patient Adjustment to Dialysis Checklist were integrated into three sub-categories to determine significance to social support systems.

Social Adjustment included positive interpersonal behavior and independence; Psychological Adjustment included psychological control; and Medical Adjustment included understanding of medical regimen, acceptance of treatment restrictions, compliance to medical regimen, compliance with dietary restrictions, and active involvement in treatment.

A chi-square analysis shows that a significant relationship does exist between the availability of social support systems and social adjustment (chi-square = 6.4, prob. $<$ .05, d.f. = 2), thus rejecting the research hypothesis; namely, that there is no significant relationship between availability of social support systems and social adjustment in chronic hemodialysis patients.

Table 4 clearly shows that 241 or 53.6% of rater responses reflected favorably in the areas of family/significant other relations, financial support systems, and community support network; 42.22% agreement and 11.33% strong agreement.

Cross-sectionally, 973 or nearly 74% of rater responses in the area of social adjustment were favorable. There is more equal distribution of responses relative to social support satisfaction (i.e. agree - 42.22%, strongly agree - 11.33%; and disagree - 37.52%, - strongly disagree 8.41% as opposed to the more unbalanced distribution of responses relative to social adjustment. That is, 930 or 76.36% of responses in agreement, 43 or 3.5% strong agreement and; 222 or 18.22% disagreement with 19 or 1.56% strong disagreement.

Table 5 depicts that a significant relationship does exist between the availability of social support systems and psychological adjustment (chi-square = 7.8, prob. $<.05$, d.f. = 2), thus rejecting the research hypothesis; namely, that there is no significant relationship between availability of social support systems and psychological adjustment in chronic hemodialysis patients. Table 4 shows that 987 or 66.78% of rater responses in the area of psychological control were agreeable and 59 or 3.99% of these responses were strongly agreeable. Significantly, 390 or 26.38% of the responses were disagreeable and 36 or 70% were strongly disagreeable.

There was no significant relationship between the availability of social support systems and medical control (chi-square = .53, prob. $<$ .05, d.f. = 2) thus supporting the research hypothesis that there is no significant relationship between availably social support systems and medical adjustment. 1677 (59.8%) of rater responses in the area of medical adjustment were agreeable and 59 (2.1%) were strongly agreeable. 942 (33.6%) were disagreeable and 39 (1.4%) were strongly agreeable. A total of 99 of 4.27% of the responses were not applicable in the instrumentation.

# CHAPTER FIVE

## SUMMARY AND CONCLUSIONS

### Social Adjustment

A statistically significant level of agreement existed between raters in the areas of positive interpersonal behavior, independence and active involvement in treatment among the patients in the study and the social worker's assessment of social support systems. The sample was largely presented as exhibiting friendly, pleasant personalities, appropriate interaction with family and staff, and their behavior was relatively free from dialysis-related stresses. The results suggest that the more the patient reached out to others and the less they relied on themselves their ability to cope was more stable. These findings tend to support the importance of maintaining and utilizing a support network in managing the stresses of a life-changing illness.

79.89% of favorable responses indicate that adjustment in positive interpersonal behavior and

independence is significant to the availability of family/significant other relations, financial resources, and community support network.

## Psychological Adjustment

Depression, anger, and feelings of helplessness are just a few of the emotions reported to be common among hemodialysis patients. The patient's ability to see self as a total person and to establish a meaningful daily routine becomes very important in terms of one's overall well-being. The finding suggest that family/significant other relations, financial support systems, and community support are related to the emotional adjustment of hemodialysis patients.

The anger and bitterness that is often expressed by the patient towards family members and staff could easily be misunderstood unless viewed in respect to its' underlying purposes. Dialysis is difficult for the patient and the negative behaviors which are sometimes displayed toward the staff are also difficult. The therapeutic services provided by the social worker have restorative benefits for the patient to maintain some meaning and purpose to living with a

life changing illness. This includes the integration of mental health, social resources, and emotional support systems. Support systems are defined as any individuals, professional activities, and/or institutions which assist the patient and family in coping. Social resources are transportation, housing, homemaker, health aid, and special equipment for life-enhancing care.

70.77% of favorable rater response in the area of psychological control might suggest a viable indicator for social work intervention as patient's mood and general demeanor changes. Close to 1/3 of the sample (27.08%) responses were rated as disagreeable and strongly disagreeable to psychological control.

## Medical Adjustment

The study indicates that patients' understanding of the medical regimen and acceptance of treatment restrictions is not related to the availability of social support systems. Compliance with dietary restrictions and medical regimen were both scored with invariable insignificance to the dependent variable.

## Limitations of the Study

The study should be regarded as preliminary because of the selectiveness of the population, the small size of the sample, and the fact that the responses were left up to the opinions of the raters. There were no self-rated scales utilized to measure patient's coping patterns, mood, levels of depression, and other significant psychosocial indicators related to crisis and other stressful events.

## Suggested Research Directions

One essential usefulness for the PADC might include enhancing adjustment goals such as helping him/her to establish a mature, interpersonal behavior with staff, experience less frequent depression, or increase communication with family.

Social workers can first ask themselves how they see each of their patient's coping styles. Do the patients tend to reach out to others or solely rely on themselves? Do they tend to avoid dealing with problems or do they attempt to confront them? Such information on the patient's coping style will not only help the social worker to better understand the patient but could prove particularly valuable when the patient

is confronted with a crisis situation. Studies designed to determine the usefulness of the PADC data, significant events in the patient's medical condition (i.e. heart attack) should also be examined. Significant correlations would suggest that the Patient Adjustment to Dialysis Checklist (PADC) is useful in signaling psychosocial adjustment problems which can be addressed through social work intervention. Changes in the Social Support Satisfaction Checklist (SSSC) ratings might indicate the usefulness of the Social Support Satisfaction Checklist (SSSC) in facilitating adjustment.

# CHAPTER SIX

## IMPLICATIONS FOR SOCIAL WORK PRACTICE

One of the most important tasks of social work practice in health-care settings are to consider the extent to which life patterns, problems, and potential for psychosocial functioning as presented by the client are affected by his/her physical condition. The biopsychosocial orientation to illness is a responsibility which involves the assessment phase and the selection of treatment goals and methods. It focuses on the knowledge of physical functioning and its impact on personality, the client's attitude toward his health, and societal views on particular illnesses and disabilities.

The work of dialysis social workers will involve helping the patient understand, accept, and cope with various physical problems. Focus will also involve assisting family members in their recognition and working through of feelings, and effective means of coping. The social worker must be able to understand the nature of the physical condition, its manifestation and effects on patients and others. The psychosocial

needs of patients are important issues in treatment as well as gaps in the availability and utilization of social support networks.

Fear of dependency centers on patient concerns about loss of control and being unable to care for self in the future. Social work intervention must acknowledge this issue, assist patients in expressing their concerns and fears in this area, and assist and encourage patients to become knowledgeable about their care. Information should be available to patients that home health care and homemaker services are available and will be utilized as needed to assist patients in remaining independent in their own homes.

Loneliness sometimes exists among patients although they maintain close contact with family and friends. The issue of quality of relationships may be more questionable than the quantity of contacts. The social worker must be aware of this concern, recognize that needs for meaningful companionship and emotional support are not being adequately met, and encourage patients in expressing their concerns and needs in this area. Counseling sessions might provide the opportunity to explore this issue in detail, identifying with patients whose barriers or problems

influencing the quality of relationships, and engaging patients and their family members in an active process of enriching those relationships.

The social worker must be aware of depression in patients and assist them in defining and ventilating their feelings of loss, discouragement and depression and the reasons for these feelings. Efforts should be made to explore with and elicit from patients, methods, techniques, or problem-solving approaches which may help them to deal with and obtain some relief from the discomfort of depressed feelings. In addition, the social worker might be helpful to share concerns and sources of depression with staff so that the treatment team can better understand, support, and coordinate their efforts in helping the patients.

The social worker could form short-term groups with formats which would engage patients and facilitate the development of a supportive network. On-going advocacy to improve the services available to dialysis patients might also serve to expand existing social support systems.

The social worker as a member of the treatment team must be able to give substantive assistance to the multi-problem patients. Social workers should enhance

the patient care team's understanding of (a) the sequence of emotional states in dialysis treatment and (b) providing information in response to patients' questions or misconceptions.

Nephrology social workers as a group have access to a strong professional organization in the council of Nephrology Social Workers (CNSW), one of the professional councils of the National Kidney Foundation. Both nationally and through local chapters, this organization provides educational meetings, information related to crucial legislative issues, and opportunities for professional support. The dynamics of the changing health structure make it imperative that we examine our role and function. Social Workers must be thoughtful, comprehensive, and show a professional manner in assuming responsibility in the team decision-making process.

The future role of the social worker will continue to include providing psychological evaluations and therapeutic interventions but the parameters will expand. The moral, ethical, and practice issues involved in helping patients and families to resolve difficulty caused by renal failure have a profound effect on the techniques and function of social work.

Patient advocacy must be strengthened and patient rights protected in the areas of respect and dignity and the right to issue a grievance. As multidisciplinary practice is extended, social workers will be utilized increasingly to serve as mediators and consultants in the resolution of team problems.

In conclusion, the importance of the social worker-patient relationship has been cited as a crucial factor which facilitates all therapeutic interventions and ultimately leads to satisfaction with the social work role. The social worker's effective use of knowledge, skills, and values is paramount to the achievement of this end.

# BIBLIOGRAPHY

Abram, H.S. (1981-82). The Psychology of Chronic Illness. Journal of Chronic Disease.

Abram, H.S. (1972). The Psychiatrist, the Treatment of Chronic Renal Failure, and the Prolongulation of Life. American Journal of Psychiatry.

Agashua P.A. and R.C. Lyle. (1981) Predicting Dietary Noncompliance of Patients on Intermittent Hemodialysis. Journal of Psychosom Res.

Beard, B.H. (1969). Fear of Death and Fear of Life. Archives of General Psychiatry.

Bommer, J., W. Tschope, E. Ritz, et al. (1976). Sexual Behavior of Hemodialyzed Patients. Clinical Nephrology.

Burton, H.J. (1983). Social Support as a Mediator of Psychological Dysfunctioning and Determinant of Renal Failure Outcomes. Clinical Exper Dialysis Apheresis.

Cobb, S. (1976). Social Support as a Mediator of Life Stress. Psychosom Medidine, 1976.

Denour, Kaplan A. (1976) The Psychiatric 627. Aspects of Renal Hemodialysis. Modern Perspectives in the Psychiatric Aspects of Surgery, New: Brunner/Mazel.

Derogatis, L.R. (1975). Psychosocial Adjustment to Illness Scale. Clinical Psychosomatic Research, Baltimore.

Diamond, M. (1979). Social Suport and Adaptation to Chronic Illness, The Case of Maintenance Hemodialysis. Res Nurse Health.

Farris, Mickie Hall, M.P.H. (1981). When Your Kidneys Fail: A Handbook for Patients and Their Families. National Kidney Foundation of Southern California.

Ford, C.B. P. Castenuovo-Tedesco. (1977). Hemodialysis and Renal Transplanation - Psychopathological Reactions and Their Managements. Psychosomatic Medicine: It's Clinical Applications. New York: Harper and Row.

Glassman, B.M. A. Siegel. (1970) Personality Correlates and Survival in a Long-term Hemodialysis Program. Archives of General Psychiatry.

Gutman, R.A., W.W. Stead, and R.R. Robinson. (1981) Physical Activity and Employment Status of Patients on Maintenance Dialysis. New England Journal of Medicine.

Hudson, Walter. (1977). New England Journal of Medicine.

Janzen, Curtis and Oliver Harris. (1986). Family Treatment in Social Work Practice, 2nd Ed., Itasca, IL: F.E. Peacock Publishers, Inc.

Lubell, Derryl, M.S.W. (1978). Pre-Dialysis Counseling. Perspectives.

Katz, A.H., D. M. Proctor. (1969). Social Psychological Characteristics of Patients Receiving Hemodialysis Treatment for Chronic Renal Failure. Kidney Disease Programs. Washington, DC: Division of Chronic Disease Program, Regional Medical Programs Service, Health Services and Mental Health Administration.

Kuther, N.C. (1981). Rehabilitation Status of Chronic Renal Disease Patients Undergoing Dialysis. Archives of Physical-Medical Rehabilitation.

Malmquist, A. (1974). A Prospective Study of Patients in Chronic Hemodialysis Predicting Factors Regarding Rehabilitation.

McKebitt, Patricia and Dean Kappel. (November 1977) Psychosocial Needs and Concerns of the Elderly on Dialysis. Perspectives 2 (1).

Minuchin, Salvadore. (1974). Families and Family Therapy. Cambridge Mass: Howard University Press.

Myers, H.F. (In Press). Social Support and Social Network Scales. A Multidimension Scale. In R. Jones, Ed. Handbook of Tests and Measures for Black Populations.

Nadelson, T. (1971). Emotional Interactions of Patients and Staff: A Focus on Psychiatric Consultation. Psychiatry in Medicine.

Nomberg, Beverly, M.S.W. (1987). It's In the Bag A Psychosocial Perspective of CAPD. Contemporary Dialysis and Nephrology.

Pentecost, R.L., B. Swevens, and J.W. Manuel. (1976). Intra Family Identity and Home Dialysis Success. Nephron.

Procci. W.R. (1981). Psychological Factors Associated With Severe Abuse of the Hemodialysis Diet. General Hospital Psychiatry.

Reichsman, F., N.B. Levy. (1972). Problems of adaptation to Maintenance Hemodialysis. Archives of Internal Medicine.

Rodin, Gary, M.D., B. Voshart. (1987). Depressive Symptoms and Functional Impairment in the Medically Ill. General Psychiatry.

Reusch, J. Joseph, S.H.W. (1972). Measurement of Social Disability. Contemporary Psychiatry. 13

Sand, P. and G. Livingston. (1966). Psychological Assessment of Candidates. Internal Medicine.

Simmons, R.G. (1983). Long Term Reactions of Renal Recipients and Donors. Psychonephrology. New York.

Stewart, Rege, szuts, M.D. (July 1983). Psychiatric Issues In Renal Dialysis and Transplantation. Hospital and Community Psychiatry.

Tucker, Carolyn M., Shirley A. Chennault, et al. (January, February 1986).Assessment of Adjustment to Chronic Homodialysis. Journal of Nephrology Nursing.

Turner, R.J. (1983). Direct, Indirect, and Moderating Effects of Social Support Upon Psychological Distress and Associated Conditions. Trends in Theory and Research. Academic Press.

Wai, L. and J. Richmond. (1976). Influence of Psychosocial Factors on Survival of Home Dialysis Patients. Clinical Nephrology.

Whalen, J.E., R.M. Freeman. (1978). Home Hemodialysis Review in Iowa. Archives of Internal Medicine.

# APPENDICES

APPENDIX A TABLES 3 - 5

APPENDIX B LETTER OF REQUEST TO CONDUCT STUDY

TABLE 3

DEMOGRAPHIC PROFILE

| Sex | Race | Age | Marital Status | Dialysis Months |
|---|---|---|---|---|
| Male | Black | 60 | Separated | 48 |
| Male | Black | 64 | Maried | 6 |
| Female | Black | 59 | Maried | 102 |
| Male | Black | 39 | Married | 100 |
| Female | Black | 60 | Widowed | 124 |
| Female | White | 67 | Separated | 24 |
| Female | Black | 60 | Widowed | 72 |
| Female | Black | 59 | Widowed | 12 |
| Female | White | 47 | Divorced | 42 |
| Male | Black | 24 | Single | 44 |
| Female | Black | 72 | Widowed | 16 |
| Male | White | 56 | Single | 10 |
| Female | Black | 67 | Married | 18 |
| Female | Black | 45 | Separated | 84 |
| Male | Black | 48 | Married | 126 |
| Male | White | 42 | Married | 58 |
| Female | White | 54 | Divorced | 17 |
| Female | Black | 70 | Single | 48 |
| Female | Black | 48 | Single | 32 |
| Male | Black | 26 | Single | 42 |
| Female | Black | 37 | Single | 137 |
| Male | Black | 60 | Single | 18 |
| Male | Black | 73 | Married | 6 |
| Male | White | 70 | Married | 24 |
| Female | Black | 56 | Married | 45 |

TABLE 4

Contingency Table

| | Agree | SA | NA | DA | SDA | RM |
|---|---|---|---|---|---|---|
| Social Support Satisfaction | 190 (42.22%) | 51 (11.33%) | 2 (.44%) | 169 (37.52%) | 38 (8.41%) | 450 |
| Social Adjustment | 930 | 43 | 4 | 222 | 19 | 1218 |
| Positive Interpersonal Behavior Independence | (76.36) | (3.53%) | (.32%) | (18.22%) | (1.156%) | |
| Psychological Adjustment | 987 | 59 | 6 | 390 | 36 | 1478 |
| Psychological Control | (66.78) | (3.99%) | (.41%) | (26.38%) | (.70%) | |
| Medical Adjustment | 1677 | 59 | 87 | 942 | 39 | |
| Understanding of Medical Regimen | (59.8) | (2.1%) | (3.1%) | (33.6%) | (1.4%) | 2804 |
| Compliance to Medical Regimen | | | | | | |
| Compliance Active Involvement in Treatment | | | | | | |
| Column Marginal | 3784 | 212 | 99 | 1723 | 132 | 5950 |

SA=Strongly Agree NA=Not Applicable DA=Disagree
SA=Strongly Disagree RM = Row Margin

TABLE 5

Result of the Relationship Between Social Support Systems and the Independent Variables

| Independent Variable | Chi-Square | Level of Significance |
|---|---|---|
| Social Adjustment | 6.4 | .01 |
| Psychological Adjustment | 7.8 | .005 |
| Medical Adjustment | .53 | .46 |

P.O. Box 2795
Macon, GA 31203-2795
March 9, 1989

Mr. Gerald Woody, Administrator
Macon Dialysis Facility
#1 Baconsfield Office Park
Macon, Ga 31211

Dear Mr. Woody:

I am conducting a research project to help meet graduation requirements for Atlanta University's Master of Social Work Degree. This study will be an attempt to describe some of the characteristics of hemodialysis patients' adaption to treatment and to discuss social work interventions which might help to enhance a more stable psychosocial adjustment.

This is to request your permission to use a random sampling of 25 patients from your facility for inclusion in this study. In addition, I would like to request your cooperation in soliciting five volunteer nurses with more than three months experience to anonomously complete the Patient Adjustment to Dialysis Checklist (PADC), and one volunteer social worker to complete the Social Support Satisfaction Checklist (SSSC) on each of the 25 patients. The instrument should not require more than 30 minutes to complete. A gratuity of $10 will be provided each staff participant.

Enclosed please find copies of the PADC and SSSC for your review, necessary comments and criticisms, and most importantly your approval. Your gracious cooperation with this study will hopefully enable me to provide you with data that will be enlightning from a problematic and patient care perspective. I will

contact you in a few days on your disposition to this request so that we may be able to arrange a time for completion of the study.

Respectfully yours,

Doris Johnson

cc/enclosure
DJ/lm